

Addressing the Psychological Needs of Families of Food-Allergic Children

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The increase in food allergies among US children has led to greater awareness of the psychological impact on their families. A variety of negative effects can result from both the daily strain of food-allergy management and the constant vigilance and fear that this condition engenders. Most of these effects are normal and expected responses to having a child with a demanding condition filled with uncertainties. However, a small but substantial proportion of families living with childhood food allergy experience significant psychological distress and/or maladaptive coping responses that interfere with the child's psychological and social development and family members' optimal functioning. Health care providers must be aware of the psychological challenges these families face, understand their role in helping families to achieve positive adaptation, and know when to encourage families to seek psychoeducational guidance.

Introduction

With the increase in the prevalence of food allergies among children in the United States has come a greater awareness of the impact on families' quality of life and psychosocial functioning [1,2]. A variety of negative effects can result from both the daily strain of food-allergy management and the constant vigilance and fear that this condition engenders. Both overresponding and underresponding patterns of adaptation to children's food allergies can place families at risk for poor outcome. In addition, parents express concern about the psychological adjustment of their children with food allergies and about the impact on relationships with spouses, siblings, and extended family members. Although many families take in stride the challenges associated with food

allergies, others struggle to achieve a positive adaptation with a balance between ensuring the child's safety while achieving normative developmental and family functions. As a result, many families need guidance, support, coping skills, and/or psychotherapy to arrive at a positive, balanced adaptation to the child's food allergies.

Unique Psychological Challenges of Food Allergy

Chronic illness in children invariably poses challenges to families' adaptation, taxing personal, psychological, emotional, and financial resources [3]. However, several unique features specific to food allergies elicit high levels of emotional distress, anxiety, and burden for parents. The most dramatic feature is the possibility of a fatal anaphylactic reaction should one's child become exposed to the food to which they are allergic. Once an individual has experienced a reaction of any severity, it is not possible to predict the severity of subsequent reactions [3,4]. A confirmed food-allergy reaction, however mild, raises the possibility of a future anaphylactic reaction, and the knowledge that such reactions can potentially lead to death often contributes to high anxiety among parents. The literature reports some controversy regarding whether parents and the population in general are being unduly frightened by the potential for death due to food-allergy reactions [5]. Although anaphylactic reactions are serious and a cause for concern, anaphylaxis to foods resulting in death is rare among children. A study from Great Britain estimated that the risk that a food-allergic child will die from a food-allergy reaction is about 1 in 800,000 per year [6]. Data from several Westernized countries suggested that among children, the incidence of fatal food reactions ranged from 1 in 3 million to 1 in 20 million per year [7].

In addition to the potential for fatal anaphylaxis, the natural course of food allergies among children poses challenges for family coping and adaptation. Food allergy has its onset in the first years of life as sensitization occurs and symptoms develop. Initial symptoms can be vague and ambiguous, and caregivers are often uncertain about the meaning of their infant's skin rashes or vomiting. Thus, suspected food allergy is relatively common in early childhood, with one fourth of parents reporting

adverse reactions to foods in their infants; in contrast, true IgE-mediated food allergy is confirmed in 5% to 10% of infants [5,8]. Parents may respond to ambiguous symptoms by implementing restrictive diets on their own, potentially putting children at risk for nutritional deficits and malnutrition [9,10].

Most food allergies remit as children get older. The prevalence of food allergy peaks at about 6% to 8% at 1 year of age, and then falls progressively until late childhood when it decreases to 2% to 4% and remains stable [8]. In addition, the persistence of specific food allergies is variable. For example, most egg, milk, wheat, and soy allergies are outgrown by school age, but most peanut, tree nut, fish, and shellfish allergies are not [11]. Parents who are aware of these patterns hope their child's food allergies will remit, and may be disappointed when the allergies persist. Alternatively, parents whose children have outgrown food allergies may have difficulty accepting the new status and may continue restrictive diets unnecessarily [12]. Children who develop one IgE-mediated food allergy have a high chance of developing more food allergies and other atopic diseases [8], and the burden for parents increases with increased numbers of confirmed food allergies [13]. As noted, for parents of children diagnosed with peanut or tree nut allergies, the typical persistence of the allergies and their association with serious and fatal anaphylactic reactions (albeit among older children and adults [6]) may contribute to extremely high levels of anxiety.

Effects of Child Food Allergy on Family Quality of Life and Psychosocial Adjustment

Effects on quality of life have been documented for families of children with food allergies by having the parents complete a nonspecific pediatric quality-of-life instrument, the Child Health Questionnaire [14]. Quality of life for children with food allergy has been compared with that of normal children and with that of children with nonallergic food hypersensitivity [15,16]. In these studies, the parents of children with food allergy had greater distress and worry and reported more interruptions and limitations in usual family activities than the comparison group. Similarly, in comparing children with peanut allergy to children with rheumatologic disease, parents of the allergic children rated significantly more disruption in daily activities and more impairment in familial-social interactions [17]. These greater disruptions and impairments were believed due to the peanut allergic children's risk of death.

Cohen et al. [13] developed a disease-specific quality-of-life instrument for parents of children with food allergies: the Food Allergy Quality of Life-Parental Burden Questionnaire (FAQoL-PB). The 17-item instrument was developed based on concerns raised by parents of food-allergic children during focus groups. Five affected

domains of family functioning were identified: family/social activities, school/camp, time for meal preparation, health concerns, and emotional issues. Although several items inquire specifically about restrictions on family activities, the overall scale focuses on emotional responses of sadness, worry about the future, helplessness, and general anxiety; total burden scores appear to represent parent emotional distress. Burden scores on the FAQoL-PB were significantly higher for families whose child had three or more food allergies and somewhat higher when the child had a previous anaphylactic reaction to food. Scores on the FAQoL-PB were significantly related to a parent's "outcome expectations" as rated on a seven-point scale (from 0 = not at all, to 6 = always) regarding the child's chances of having a serious reaction and dying upon ingesting the food to which he/she is allergic. Because incidence of death due to food allergy is extremely rare, parents who rate as high their child's chance of dying from food-allergy reactions would seem to be revealing that their high levels of anxiety and fear about food exposure resulting in serious or fatal anaphylactic reactions are the primary component of the emotional burden they experience. In this study, high burden was weakly associated with a history of anaphylaxis; however, other investigators have noted that parents' anxiety was not related to whether their child had an anaphylactic reaction, but rather to the perception of the risk of such reactions in the future [18•].

Although quality-of-life studies indicate that children's food allergies affect parents' emotional distress and family activities, only recently have studies evaluated the proportion of families who experience either moderate distress or debilitating psychosocial effects as a result of their child's diagnosis of food allergy. The Food Allergy Impact Scale was developed to assess the impact of food allergy on the daily activities of families living with childhood food allergies [18•]. Of 87 caregivers of children with food allergies, 70% reported a significant impact on meal preparation, which is not surprising because changes in food preparation are central to the lifestyle changes required for these families, and the time required for grocery shopping and preparing special meals is known to impact quality of life [15]. Similarly, 79% of families reported significant impact on going to restaurants, and 16% said they do not go to restaurants at all because of food allergy. Of concern, a substantial number of caregivers reported that food allergies kept them from engaging in activities that are central to family members' full participation in developmentally appropriate activities. Ten percent reported not engaging in activities with relatives, 11% did not allow their children to play at friends' houses, 10% did not send their children to birthday parties, and 10% reported home schooling their children because of their food allergies.

Another study evaluated psychological adjustment to childhood food allergies among 221 parents who sought

treatment for their children at allergy clinics and who attended food-allergy support groups [19•]. Although 51% of parents reported that much or most of the time they are afraid for their child's safety because of the allergies, less than 10% reported becoming tearful when they think about the problem and/or feeling helpless to deal with it. Negative effects on the child's social and psychological development were reported by 5% or less, whereas 8% reported their family was unable to do usual activities because of the allergies. In sum, available data suggest that although the majority of families with a food-allergic child report expectable impact on meal preparation, half experience a pervasive fear for their child's safety and a sizable subgroup restricts normal child and family activities because of the food allergies.

Parent anxiety

The literature suggests that the fear of accidental exposure that could result in death underlies the pervasive anxiety among families whose children have food allergies [15–17,20,21]. However, new studies suggest that for most parents, anxiety levels fluctuate over time, and that moderate levels of anxiety among parents of food-allergic children may be helpful. It is natural for parents to experience high levels of anxiety at the time of diagnosis, when they are typically warned that accidental exposures may lead to anaphylactic allergic reactions and even death. The anxiety initially experienced by parents may serve to motivate the behavior necessary for developing an adequate management system for the food allergy [22]. In a qualitative study with families of food-allergic children who had experienced anaphylactic episodes, remarkable consistency was observed in the processes by which families described their adaptation. Parents reported initial high levels of anxiety that motivated them to obtain information about food avoidance and risk management. Once strategies were in place, anxiety was reduced and a high level of vigilance prevailed. If anxiety fell too low, the level of vigilance tended to drop. Three key events triggered a rise in anxiety: reactions due to accidental ingestions; new information regarding potential risk; or developmental transitions that threatened increased exposure to risk. These events motivated families to obtain new information and to extend and improve their management system [22]. Thus, for parents of children with food allergies, some anxiety—short lived and related to key events—is to be expected and may even be helpful.

However, some families are unable to return to a less anxious state. Whether or not their child has accidental ingestions or reactions, they remain highly anxious and distressed; at this level, family members report experiencing a dysfunctional level of stress and fear [22]. Often this is driven by the possibility of a fatal anaphylactic reaction, which remains continuously salient to family members. Children and their families may become “paralyzed” with

fear of a reaction [23]. Such anxiety may be manifested as distorted perceptions of the real dangers faced by their child, and may lead to extreme behaviors, which are intended to protect the child but are in fact unnecessary. For example, because they fear a fatal reaction, parents may choose to home school their child or not allow age-appropriate outings, choices that have implications for the child's normal growth and development [23]. Although data are lacking regarding the underlying psychological process, such restrictions appear to reflect an overresponding pattern of behavior that may be driven by anxiety and would be unnecessary if coping strategies were adequate.

Psychological aspects of food-allergy management

Management of food allergies involves avoiding foods to which children are allergic, being prepared to respond to accidental exposures, and training the child's other caretakers to respond in kind. Among families referred to an allergy clinic in the United Kingdom, a pre-intervention baseline questionnaire revealed that only 40% of families knew which foods to avoid [24]. Further, large deficits were found in families' knowledge of how to guide their children in food avoidance during participation in social and academic activities outside the home.

Several studies have found that an alarming number of caregivers lack knowledge of anaphylactic symptoms that require immediate treatment, do not have epinephrine autoinjectors available, lack knowledge required to use an autoinjector effectively, or have not used it when an anaphylactic reaction occurred [25–28]. In an examination of parents' projected comfort with administering an epinephrine autoinjector (EpiPen; Dey, Napa, CA, USA) to their children, almost half reported they would feel outright uncomfortable. Reasons given for their discomfort included inability to recognize the symptoms of anaphylaxis (51%); fear of hurting their child (40%); and thoughts that they would forget how to use the EpiPen in a high-pressure situation (36%) [29•]. Parents' projected comfort with EpiPen administration was predicted by their sense of empowerment, whereas neither a history of anaphylaxis nor knowledge correlated with an increased level of comfort with administration [29•].

Child adjustment and self-management

A 2003 study that compared quality of life among 7- to 12-year-olds—half of whom had peanut allergy and half of whom had insulin-dependent diabetes mellitus—demonstrated that children with peanut allergy reported poorer quality of life, with greater fear of an adverse event and more anxiety about eating [30]. Despite overall increased anxiety, the children reported feeling safe if they had their epinephrine kits available and if they ate at familiar restaurants. Because these are specific key strategies for effective food-allergy management, this illustrates the close relationship between effective illness management and better psychosocial adjustment.

As with their parents, some anxiety in relation to having food allergies may be normal for affected children, and may even be helpful for motivating self-management. As children proceed through stages of cognitive, emotional, and social development, their emotional responses and self-management strategies evolve. Clinical experience suggests that an increase in anxiety occurs in some children at around age 7, as their cognitive development allows them to appreciate the possibility of serious reactions and as they move toward more independent functioning at school and with peers. For example, teasing or bullying by schoolmates may involve threats of exposure to the food, which may increase children's anxiety and distress [23]. Little is known about the persistence of these anxiety responses, or about the frequency of clinically significant anxiety reactions in children living with food allergies. It is known that some children with food allergy develop debilitating levels of anxiety, most often related to a fear of exposure to the food to which they are allergic [31•].

The transition from childhood to adolescence marks another time of increased risk. Although fatal food-allergy reactions are rare, they are most common among teenagers and young adults [32,33]. Recent studies indicate this may be due both to willingness to take risks and to faulty perceptions of risk [34]. In an Internet-based questionnaire study with food-allergic youth ranging from 13 to 21 years of age, 54% of 174 respondents indicated they had purposefully ingested at least a tiny amount of food that was known to contain an allergen [35•]. Reasons for doing so included experiencing previous exposures without reactions, risky judgments about the safety of foods, and simply wishing to eat the food. In addition, 61% reported they always carry epinephrine, but further inquiry showed that frequency of doing so varied by social situations, convenience, and perceived risk [35•].

Assessing and Addressing Families' Psychological Needs

The diagnosis of food allergy in children clearly presents significant challenges to families if they are to ensure their child's health and safety and promote optimal functioning for all family members. Multiple interpersonal challenges can tax families as they attempt to ensure their child's safety among friends and relatives. Informed assertiveness is necessary for communicating effectively with restaurants and other systems, such as day care, schools, and camps. The lifestyle changes and coping requirements are challenging for the well-adjusted parent with ample financial, social, psychological, and interpersonal resources and skills. Those with difficulties or deficits in these areas are at a disadvantage and frequently encounter challenges in achieving a positive adaptation. Therefore, families not only may experience high anxiety

that waxes and wanes, but they also may have a variety of unique psychosocial needs related to adequate coping with their child's food allergies.

The health care provider's role

It is difficult to overestimate the psychological influence of the medical evaluation and the health care provider's approach to providing feedback and guidance regarding children's food allergies. For example, the anxiety level of parents has been demonstrated to decrease significantly from before to after a comprehensive food-allergy evaluation, whether or not the suspected food allergy was confirmed [36]. Presumably, reducing uncertainty and supplying unambiguous instructions for managing the food allergies were responsible for decreasing the parents' anxiety. Although this study involved clarification at initial diagnosis, the same process likely occurs at the follow-up evaluations intended to test for the remission versus persistence of specific allergies. Medical re-evaluations are an extremely useful tool for addressing the psychological and management needs of families and children. This is especially true for adolescents. Because young teens may not remember an allergic reaction experienced earlier in life [34], the objective feedback in the clinic provides evidence of continued sensitivity (or lack thereof), involves the teen in planning avoidance and management strategies [35•], and aids in the process of shifting self-management responsibility from the parent to the adolescent.

Although the medical evaluation is a powerful psychological intervention, it also presents an opportunity to assess families' adaptation to their children's food allergies. The behavior of parents and children may indicate psychological distress or suboptimal functioning that warrants intervention. Parents may directly express how worried and anxious they are, become tearful, or obsessively question details of exposure or management, thus indirectly revealing high levels of anxiety. Moreover, parental reports that they have restricted family social activities or interactions or that the child is unable to attend school, camp, or social activities due to their food allergies merit exploration.

On the other hand, children's behavior during the evaluation and feedback meetings may reveal difficulties with adaptation. They may become tearful, display fearfulness, or report peer problems that they attribute to their food allergies. Further indications of child emotional difficulties could include fears of testing procedures or of oral food challenges. Additional areas of concern may include the child's lack of interest in learning about their allergies and their role in management. Observed interactions between parents and children or teens, if impoverished or conflicted, may be an indication that the food-allergy management system is awry. Any of these behavior patterns by parents or children may indicate that a family is having difficulty adapting to the child's food allergies in an effective and positive manner,

and merits at least a brief quality-of-life assessment by a psychosocial clinician with experience and expertise.

Psychosocial interventions

We have found that an assessment of quality of life as related to food allergy is useful both to determine whether families are having difficulty maintaining a balance and as a brief therapeutic intervention. The aim of our 1.5-hour brief assessment is to optimize families' quality of life by recognizing the specific challenges they face and helping them find coping strategies to address the challenges. Before the meeting, parents complete the FAQoL-PB and rate their outcome expectations [13]. Next, we conduct a clinical interview focusing on the areas that parents rated as most affecting their quality of life. The interview includes questions about their food avoidance strategies and preparation for reactions.

Several patterns of adaptation, both positive and negative, have emerged from the brief assessments. Many of the parents who reported high anxiety about their child's food allergies had high FAQoL-PB burden scores and rated as high their child's chance of dying from the food allergies. Such ratings were almost always associated with strategies such as home schooling or restricting social activities. On the other hand, some parents reported not feeling burdened by their child's food allergies; they had low FAQoL-PB burden scores and rated their child's chance of dying as low. However, the interview revealed overly casual food avoidance strategies or, more commonly, a failure to have injectable epinephrine always available in all settings in the event of an anaphylactic reaction. Finally, some families demonstrated a balanced pattern of response to their child's food allergies. They presented with low FAQoL-PB burden scores. These families realistically rated their child's chance of having a severe food-allergy reaction as high, but their child's chance of dying as low. The food-allergy management strategies that these families utilized were thorough and complete, and the parents consciously worked at ensuring their child's participation in developmentally appropriate activities.

Whatever the family's pattern of adaptation, opportunities arise for therapeutic interventions. Parents have found it helpful to complete the quality-of-life questionnaire, because doing so reassures them that their concerns are shared by other parents of children with food allergies. It is helpful for them to learn that the cycles of anxiety they and other families experience are normal and predictable responses to their child's condition. However, they also have an opportunity to evaluate the appropriateness and tolerability of their own anxiety level, and to examine the ways in which it may be motivating unbalanced behavior. Parents having difficulty managing their anxiety inevitably trace it to their fear of a fatal anaphylactic reaction. For many families, a single session is helpful, whereas others recognize that further

individual, family, or couples work is indicated, and they initiate follow-up psychotherapy.

Conclusions

We have presented evidence that having a child with food allergies produces a variety of psychological effects on parents and children. Most of these effects are normal and expected responses to having a child with a condition that is demanding, yet filled with uncertainties. However, it appears that a small but substantial proportion of families living with childhood food allergy experience significant psychological distress and/or maladaptive coping responses that interfere with the child's psychological and social development and family members' optimal functioning. Health care providers must be aware of the psychological challenges these families face, understand their role in helping families achieve positive adaptation, and know when to encourage families to seek psychoeducational guidance.

Disclosures

No potential conflicts of interest relevant to this article were reported.

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